DOCUMENT RESUME

ED 307 756 EC 220 261

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TITLE Permanency Planning for All Children and Youth: Policy and Philosophy To Govern Out-of-Home Placement Decisions.
INSTITUTION Syracuse Univ., NY. Center on Human Policy.
PUB DATE 88
NOTE 22p.
PUB TYPE Viewpoints (120)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Children; Family Environment; Individualized Programs; *Long Range Planning; *Placement; *Policy Formation; Program Development; Residential Programs; *Severe Disabilities
IDENTIFIERS *Permanency Planning

ABSTRACT

The paper advocates the extension of the basic protections of "permanency planning" to all children and youth, including those with severe handicaps. It discusses the concept and process of permanency planning and notes its promise in improving the opportunities of all children and youth to grow up in a stable family environment. It demonstrates the need for major initiatives in this area by providing statistics on the number of children and youth with mental retardation in long-term care settings without such protections. It describes current programs operating according to the principles and procedures of permanency planning. It recommends significant changes in existing federal policy to require permanency planning as part of all considerations of federally supported out-of-home care for all children, including those with severe disabilities. (Author)

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PERMANENCY PLANNING FOR ALL CHILDREN AND YOUTH: POLICY AND PHILOSOPHY TO GOVERN OUT-OF-HOME PLACEMENT DECISIONS

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Permanency Planning for All Children and Youth: Policy and Philosophy to Govern Out-of-Home Placement Decisions[1]

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Abstract

This paper advocates the extension of the basic protections of "permanency planning" to all children and youth, including those with severe handicaps. It discusses the concept and process of permanency planning and notes its promise in improving the opportunities of all children and youth to grow up in a stable family environment. It demonstrates the need for major initiatives in this area by providing statistics on the number of children and youth with mental retardation in long-term care settings without such protections. It describes current programs operating according to the principles and procedures of permanency planning. It recommends significant changes in existing federal policy to require permanency planning as part of all considerations of federally supported out-of-home care for all children, including those with severe disabilities.

Permanency Planning for All Children:
Policy and Philosophy in Developmental Disabilities

In 1978, the Children's Defense Fund (CDF) issued a report, *Children Without Homes* (Knitzer, Allen, & McGowan, 1978) that indicted federal and state governments for complicity in depriving about 500,000[2] children of the benefits of growing up in a stable family environment. In the Preface, Marion Wright Edelman, Director of CDF, wrote:

> At the federal level there is a pressing need for strong leadership and legislative reform. Particularly crucial is the passage of child welfare legislation which would: erase federal fiscal incentives to keep children in out-of-home care; increase funds for preventative and restorative services; strengthen protections for children and families; and ensure children permanent families (p. xiii).

Spurred by the CDF report, the advocacy of a range of child welfare groups, and changing perspectives within the field of child welfare, Congress enacted Public Law 96-272, the Adoption Assistance and Child Welfare Act of 1980. P.L. 96-272 was a direct response to the "anti-family bias" and pervasive problems characterizing the child welfare system at that time. Among these problems were that: (1) more children were placed in foster care and other out-of-home settings than considered necessary or appropriate; (2) too many children remained in foster care and other settings too long and with little hope of either returning to their natural families or being freed for adoption; and (3) children in foster care and other out-of-home placements often bounced from setting to setting with few prospects for a stable family life.

P.L. 96-272 represented an important shift in federal policy away from support of out-of-home placements and toward support of home and family living. The law was intended to put an end to "foster care drift" and makes reference to "reduction in the duration of foster care for children." As Grimm (1985) wrote about the context in which the bill was passed:

> Among other problems in foster care, national studies had documented that many children lingered in temporary foster care placements for years, never returning home to their parents of becoming permanent members of new families. Congress sought to put an end to this foster care drift by imposing

> a mandatory review system upon the states and the local child welfare agencies which were responsible for foster children. (p. 24)

To receive funds under P.L. 96-272, Congress mandated states to comply with "permanency planning" for children in foster care and other out-of-home settings (Maluccio, Fein, & Olmstead, 1986). Yet while permanency planning has become a central feature of child welfare policy, its influence is limited among agencies focused on developmental disabilities. Not only are such agencies not covered by the requirements of P.L. 96-272, they are usually unfamiliar with the principle of permanency planning, its premise that a stable family life and enduring relationships with adults are essential to the development and well-being of children, and its promises that when social services agencies are involved in the lives of children they will be committed above all else to meeting the need of all children for a permanent family.

This article explores the applicability of the philosophy and policy of permanency planning for children with developmental disabilities. It examines the status of children with developmental disabilities in out-of-home settings, discusses permanency planning in federal and state policy, and advocates adopting the concept as a guiding principle for the activities of all agencies serving children and families, including those serving children with developmental disabilities and their families.

Children with Developmental Disabilities Out-Of-Home

The number of children with developmental disabilities placed out-of-home, whether in foster care, small group facilities, or institutions, has declined substantially over the past decade. In just 6 years, from January 7, 1980 to December 31, 1985 the number of children and youth (birth to 21 years) with mental retardation in generic (social services/child welfare) foster care decreased from 21,400 to an estimated 13,900, or about 35% (Hill, Lakin, Novak, & White, 1987). In just 9 years, from June 30, 1977 to June 30, 1986 the number of children and youth with mental retardation in state administered long-term care programs decreased from 91,000 in 1977 to 60,000 in 1982 to an estimated

48,450 in 1986, or about 45% (Lakin, Hill, & Bruininks, 1985; National Center on Health Statistics, 1987). Many factors have contributed to this trend, but the passage of Public Law 94-142, the Education for All Handicapped Children Act of 1975, was probably the most important. It helped assure that children would not be pushed out of home solely in order to receive educational/developmental services. It also provided parents of children and youth with severe disabilities, often previously excluded from school, with daytime respite and the opportunity to pursue employment and leisure activities.

Yet, despite the decline in the number of children with disabilities placed out-of-home, an estimated 62,350 children and youth with mental retardation remained in out-of-home residential placements on June 30, 1986. These numbers include an estimated 13,900 children with mental retardation in generic social services/child welfare foster care whose placements fall under the guidelines of the permanency planning provisions of P.L. 96-272. These numbers also include about 48,450 children and youth with mental retardation in long-term care programs operated by state and regional mental retardation/developmental disabilities agencies, as estimated by the Inventory of Long-Term Care Places (National Center on Health Statistics, 1987) and the Recurring Data Set Project at the University of Minnesota (Lakin, Hill, White, & Wright, 1988). These are children and youth for whom "permanency planning" in the sense envisioned in P.L. 96-272 is rare. Of the 48,450 children and youth with mental retardation (21 years and younger) in such long-term care settings, approximately 7,150 were among the 19,100 total residents of state-sponsored specialized foster care settings, 24,000 were among 132,500 persons with mental retardation in private (non-foster) and small public residential facilities, and 17,300 were among the 100,100 residents of large state institutions. Assuming age distributions among these populations identical to those found in the most recent research providing age breakdowns (see notes in Table 1), the age distributions of

children and youth with mental retardation in the different types of "facilities" would be approximately as shown below in Table 1.

Insert Table 1 About Here

The "generic foster care" column of Table 1 represents those children and youth in programs covered by the provisions of P.L. 96-272, to whatever extent they may be applied in practice. The larger group of children and youth in state mental retardation agency administered programs are shown in the "specialized foster care," "private and small public facilities," and "state institution" columns. A number of observations can be made from Table 1. First, and perhaps most important, only about 22% of the children and youth with mental retardation in out-of-home care are in placements administered by social services/child welfare agencies. Second, the younger a child with mental retardation is, the more likely he/she is to be potentially covered by the provisions of permanency planning: 50% of 0-4 year olds; 36% of 5-9 year olds; 28% of 10-14 year olds; and 13% of 15-21 year olds. Third, the estimated number of children and youth with mental retardation growing up in either generic or specialized foster homes (21,000) is not much larger than the number of children and youth with mental retardation in state institutions (17,300) and the number of youth 10 years and older with mental retardation in foster care (14,400) is actually less than the number growing up in state institutions (15,800). Fourth, nearly twice as many children and youth with mental retardation in out-of-home placements are growing up in public and private congregate care settings (41,300) than in foster homes (21,000). While many congregate care settings attempt to emulate aspects of family life, they are naturally quite limited in their ability to do so.

Permanency Planning and Federal Policy

P.L. 96-272 has had two major impacts on child welfare programs. First, P.L. 96-272 established a new Title IV-E of the Social Security Act to provide federal matching funds for adoption subsidies for "special needs children" in foster care or child care institutions, as well as funds for foster care programs. States receiving federal foster care funds were required to participate in the federal adoption assistance program. For a child to be eligible for an adoption subsidy three conditions were specified: (1) the biological parents or custodial relative must meet financial eligibility criteria (generally eligibility for Aid to Families of Dependent Children or Supplemental Security Income); (2) the child must have "special needs," resulting from factors such as age, race or ethnicity, medical conditions, or "physical, mental, or emotional handicaps"; and (3) efforts to place the child in an adoptive family without subsidy have been unsuccessful.

Second, P.L. 96-272 mandated a set of permanency planning procedures for state welfare agencies receiving funds for children in foster care or child care institutions. The major requirements of these procedures include the development of a written "case plan" and the establishment of a "case review system" for each child. The case plan is defined in P.L. 96-272 as "a plan for assuring that the child receives proper care and that services are provided to the parents, child, and foster parents in order to improve the conditions in the parents' home, facilitate return of the child to his own home or the permanent placement of the child, and address the needs of the child while in foster care."

The "case review system" is defined in P.L. 96-272 as a procedure for assuring that "each child has a case plan designed to achieve placement in the least restrictive (most family like) setting available and in close proximity to the parents' home, consistent with the best interest and special needs of the child." The case review system includes at least two reviews: (1) a six month review by a court or administrative body, which can

include a citizens review board, of the appropriateness of placement, compliance with the case plan, progress towards addressing the reasons for placement, and a projected data by which the child can return home or be placed for adoption; and (2) an 18-month "dispositional hearing" (and periodically thereafter) by a court or court-approved administrative body on the child's future status, including return to the parent, continued foster care placement, adoption, or permanent foster care.

While P.L. 96-272 undoubtedly has had a major impact on child welfare agencies and contributed to improving the lives of many children served by those agencies, the law is characterized by a major flaw regarding children with disabilities. Since P.L. 96-272 applies only to public welfare agencies, children served by state mental retardation/developmental disabilities agencies are not included under the protections of the law. As noted previously, only about 22% of children and youth with mental retardation placed out-of-home are in "generic foster care." It is only these children who benefit from the protections of P.L. 96-272 even though, ironically, children with physical, mental, or emotional handicaps were singled out as having "special needs" in the legislation.

For children with developmental disabilities, current federal programs still promote out-of-home placement. The largest of these programs in terms of federal contributions, the Medicaid ICF-MR program, is focused only on persons in congregate care. The "Medicaid waiver" options, including the Medicaid home and community-based services wavier and the so-called "Katie Beckett" model serve relatively small numbers (just over 23,000 on June 30, 1986) and tend to be oriented toward people who are already in state long-term care systems (Lakin, Hill, Bruininks, Greenberg, & Schmitz, 1985; Lakin, Hill, White, & Wright, 1987).

On a federal policy level, there are two major changes needed to further the rights of children with developmental disabilities to a permanent home. The first is a revision

of P.L. 96-272 to encompass *all* children placed out-of-home by any public agency, not just those receiving funds under the Act. The protections of P.L. 96-272 should apply to all children in any state in which funds are received under P.L. 96-272. The second major change needed is incorporation of permanency planning requirements into all federal programs providing benefits to children and youth with disabilities, including direct residential services, as through Medicaid, ancillary residential services, as through the residential component of residential schools funded by P.L. 89-313 and P.L. 94-142, and indirect residential services, as "purchased" with cash assistance through Supplemental Security Income and Social Security Disability Insurance.

Permanency Planning and State Policy

Just as the federal government has excluded most children with mental retardation from the protections of P.L. 96-272, very few states have incorporated permanency planning into their mental retardation system policies and procedures. The Michigan Department of Mental Health, one notable exception, describes regarding its own past practices:

> ...a double standard has existed in Michigan for those children placed with the child welfare system and those children placed with the mental health system. Permanency planning of children entering the child welfare system is required by both federal and state law to insure that children enter care only when necessary, are reviewed periodically, and provided permanent families in a timely fashion. There has been no similar requirement for children voluntarily placed in care with the Michigan mental health system...these children have not been provided the protections of a system oriented toward a child's need for permanency. (1986, p. 3-4)

The issue of permanency planning highlights the disjointed nature of child care systems in most states. Most states operate dual systems for children: the social services/child welfare system and the mental retardation/developmental disability system. Not only do most states operate separate child welfare and developmental disability residential programs, but jurisdictional disputes and ambiguities between agencies regarding responsibility for children with developmental disabilities are common (Taylor & Racino,

1987). Child welfare or social service agencies may claim that they do not have the expertise to serve children with developmental disabilities. Mental retardation or developmental disability agencies may lack of authority, resources, or experience to pursue permanency planning and adoption.

To exemplify these problems, the University of Minnesota survey of state social services agencies (Hill, Lakin, Novak, & White, 1987) provided a hypothetical example of an 8 year old boy with mental retardation whose family was no longer able to care for him at home. Respondents were asked what factors would determine whether this child went into a child welfare foster home under the guidance of permanency planning, or state mental retardation/developmental disabilities agency sponsored residential or foster care placement. Responses evoked a picture of two generally disjointed systems in which decisions about placing children were more often expressed in terms of agency needs than in terms of individual children's needs. Many respondents indicated that the placement of the child was dependent on the availability of homes, the particular agency first contacted, or the resources available in each agency to fund new placements. In at least seven states placement in a generic foster care home could not be made without some type of legal/court procedure (e.g., charges of abuse or neglect), propelling "voluntary" placements away from the protections of P.L. 96-272. Numerous respondents noted that a major incentive for moving children and youth into state mental retardation agency sponsored programs was the greater levels of available funding through state and federal sources.

While the federal government and most state developmental disability agencies continue to ignore the rights of children with developmental disabilities to permanency and stability in their lives, a few states have begun to address permanency planning in policy and practice. Michigan's Department of Mental Health stands out as the first state agency to adopt permanency planning as a guiding principle for children with

developmental disabilities. Consistent with the Governor's (1984) goal that no child with developmental disabilities be institutionalized in the state, Michigan has developed a range of family support programs, including a family subsidy, and has incorporated permanency planning into state policy and procedures. Michigan (1986) operates under the following definitions and assumptions:

> Definition of permanency planning:
>
> A planning process undertaken by public and private agencies on behalf of developmentally disabled children and their families with the explicit goal of securing a permanent living arrangement that enhances a child's growth and development. Permanency Planning for children is directed to securing:
>
> 1) a consistent, nurturing environment;
> 2) an enduring, positive adult relationship; and
> 3) a specific person who will be an advocate for the child into adulthood.
>
> Underlying assumptions:
>
> 1) It is generally in the best interest of children to remain at home with their family. Therefore, public agencies should first attempt to plan, provide, and coordinate services in such a manner that the integrity of the family unit may be *maintained*.
>
> 2) If a child cannot be maintained in the home, it is assumed that a public agency should then give priority attention to the provision and coordination of those services that will facilitate *reunification* of the child with his/her family at the earliest possible time after placement out of the natural home.
>
> 3) If reunification of the child with his/her family is not possible, and there is no active parental involvement with the child, the feasibility of adoption planning should be rigorously pursued.
>
> 4) For some children, already in care, strengthening the ties with the birth family by increasing the quality of involvement while the child remains in foster care may be the most appropriate permanency planning option. For certain other children, the permanency planning path may include such alternatives as long-term foster care, supplemented by securing an advocate or a guardian.
>
> 5) Institutionalization is not considered to be an appropriate permanency planning option. (p. 5-6)

Based on a statement developed by the Center on Human Policy (1987) and subsequently endorsed by the Board of Directors of the Association for Retarded Citizens of the United States (1987), Nebraska's Unicameral Legislature passed the "Family Policy

Act" that endorses permanency planning for all state agencies concerned with or responsible for children and families (GOARC Gazette, 1987). Nebraska's law reads:

> When children are removed from their home, permanency planning shall be a guiding philosophy. It shall be the policy of the state to reunite the child with his or her family in a timely manner if reunification is in the best interest of the child; and when families cannot be reunited and when active parent involvement is absent, adoption shall be aggressively pursued. Absent the possibility of adoption other permanent settings shall be pursued. (GOARC Gazette, 1987, p. 8)

Finally, in its most recent five-year plan, Connecticut's Department of Mental Retardation (1987) endorsed the philosophy that "All children, including children with mental retardation, need a permanent home and enduring relationships with one or more adults" (p. 43).

Permanency Planning as a Philosophy

Permanency planning is first and foremost a philosophy. It is a way of thinking about and valuing children and families. But permanency planning can be reduced to a bureaucratic exercise without success in bringing about the desired result and without commitment to the underlying philosophy (see the *Syracuse Herald-Journal*'s [January 10-15, 1988] five-part series entitled "The Disposable Children").

Central to permanency planning is the belief that all children, regardless of disability, belong in families. It provides clear direction when government is involved with children and families. It assumes, as did Wickenden in the Foreword to CDF's *Children Without Homes* (1978) that:

> ...when government assumes responsibility for children, it owes them the kind and degree of nurture children require for their development...Children require, before all else, the sense that they belong to reliable and loving adults who will care for their needs, emotional as well as physical...Children require stability, most particularly an inner assurance that caring adults will remain firmly in their lives. (p. x-xi)

As a guiding orientation to services for children and youth with developmental disabilities, permanency planning implies the following principles.

Support the family. Permanency planning is based on the principle that agencies should provide "whatever it takes" to enable children to grow up in families. Years after Ed Skarnulis admonished agencies to "Support, don't supplant the family," states have begun to allocate funds for family support services (Taylor, Racino, Knoll, & Lutfiyya, 1987). As of 1985, 49 of the 50 states had established some form of family support programs for children with developmental disabilities (Bradley & Agosta, 1985). But, in most states, family support programs reach too few families and/or provide too little support to meet existing need. Often the services available in family support programs are too inflexible to meet the broad range of needs among individual families (Bradley & Agosta, 1985; Taylor, et al., 1987). While families may have such diverse needs as home modifications, transportation, and in-home supports, family support programs are often limited to one or two services, most often out-of-home respite care.

In contrast to the more limited an inflexible family support programs, a few states and agencies have established "family centered" support programs based on families' actual needs and preferences (Taylor, et al., 1987). Wisconsin has a flexible voucher system, available in selected counties, that can fund a broad range of formal and informal supports needed by families. In addition to other family supports, a number of states now provide selected families with cash subsidies that can be spent on almost anything that will help maintain the child in the family. Michigan's family subsidy program currently provides $255 per month to over 2,000 families of children with severe developmental disabilities.

Encourage family reunification. All families cannot at all times maintain their children at home. Crises or other circumstances may require out-of-home placement. Historically, out-of-home placement of persons with developmental disabilities has been viewed as a permanent disposition. In many cases, agencies actually discouraged a

family's involvement with a child after placement. As noted by Michigan's Department of Mental Health (1986):

> We though we were being helpful by relieving the family of the responsibility and encouraging them to separate from their child after placement. We offered advice to not visit the child after placement...so that the family and child could adjust to the separation. (p. 3)

Permanency planning recognizes the importance of and irreplaceability of family ties, and, therefore, requires substantial effort to ensure ongoing parental contact after placement to facilitate family reunification. A major principle underlying permanency planning is that it is a very rare instance when a child is not better off in his/her natural family. It is, therefore, the responsibility of any agency involved with children and families to utilize its resources effectively to reunite families whenever feasible.

Pursue adoption. For children whose ties to their families have been permanently broken, adoption is the option of choice in permanency planning. Once considered an unrealistic goal, recent experience has demonstrated that adoptive families can be found for children with a range of severe disabilities (Nelson, 1985). In Hartman's (1985) words: "Adoption, rather than a privilege for the perfect infant, was reconceptualized as a right for all children who cannot find permanence with their biological families. The motto and the goal of adoption today has been expressed in the statement, 'No child is unadoptable'" (p. 59). Still, mental retardation/developmental disabilities agencies continue to set up obstacles to adoption. A review of one state's specialized foster care program found that mental retardation agencies not only do not pursue adoption, but may actively discourage foster families from adopting children in their homes (Taylor, Lutfiyya, Racino, Walker, & Knoll, 1986). Under the principles of permanency planning, for any child unable to be reunited with his/her natural family, an adoptive family would be the objective of choice for the agency serving the child's best interests.

Explore other permanency options. Because of legal barriers or a family's continued involvement with a child, adoption is not always an option. In such instances,

permanency planning directs attention to other options to insure stability in children's lives. These options include "permanent" foster care, a court-sanctioned or informal agreement for a child to remain with a foster family until adulthood, or "shared care" or "co-parenting" in which a natural, or biological, and foster family share responsibility for raising a child. In addition, "open adoption," in which a child's ties to his or her biological family are kept intact, is increasingly viewed as the most appropriate option for many children, especially older ones. Hartman (1985) states, "Older children have memories, connections, important relationships. They have a past" (p. 73).

Discussion

Today the orientation of services for children and youth with developmental disabilities stands at much the same place as child welfare stood ten years ago. Then advocates drew attention to the anti-family bias of social services programs and demanded a change in legislation and agency practices. Numerous problems continue to surround child welfare services, but the permanency planning provisions of P.L. 96-272 established clear and important principles by which state and local agencies are expected to deal with situations in which children are in or at risk of out-of-home placements.

As a concept applied to programs for persons with developmental disabilities, permanency planning would call for a major changes in both policy and philosophy guiding service provision. Instituting permanency planning for *all* children and youth will require attaining as many of the following objectives as possible:

1. Secure a revision of P.L. 96-272, the Adoption Assistance and Child Welfare Act of 1980, to require the implementation of permanency planning protections in all agencies of participating states including those serving children and youth with disabilities.

2. Creating a federal requirement, perhaps through amendment of P.L. 96-272, for permanency planning whenever federal program benefits are used to purchase long-term out-of-home care for children and youth (including programs such as Medicaid, P.L. 89-313, and P.L. 94-142 funded "schooling," Supplemental Security Income, and others).

3. Incorporating permanency planning in state and local laws and regulations governing services for children and youth with disabilities.

4. Shifting state, local, and private agency philosophy and practices toward: (a) more flexible and individualized family support services to maintain children at home; (b) stronger efforts at family reunification for children placed out-of-home; (c) more vigorous pursuit of adoption for children whose ties to their families have been broken; and (d) basic assurances of other family-based options for children who cannot be reunited or be freed for adoption designed to insure stability of their lives and enduring relationships with adults.

5. A clear commitment on the part of all persons, advocates, professionals, and policymakers to the proposition that all children and youth should be assured the opportunity to grow up in stable family situations, that "family-like" alternatives be used only when absolutely necessary and for no longer than absolutely necessary, and that public resources should be redirected toward supporting children in families.

The concept of permanency planning raises fundamental questions regarding the place of people with disabilities in our society and our communities. It is a cultural expectation that children will live with their families. Only extraordinary circumstances call into question the nondisabled child's place in the family. For children with disabilities, however, the cultural standard has too often been waived. A universal permanency planning policy would mean that all children and youth, including those with severe disabilities, would be provided with the greatest possible opportunity to enjoy and benefit from family living.

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Table 1

Estimated Age Breakdown of Children and Youth with Mental Retardation in Out-of-Home Placement

Ages	Generic Foster Care[1]	Specialized Foster Care[2]	Private & Small Public Facilities[3]	State Institutions[4]	Total
0-4	1,906	592	960	320	3,778
5-9	2,936	1,185	2,888	1,173	8,182
10-14	4,453	1,912	6,275	3,298	15,938
15-21	4,605	3,461	13,877	12,509	34,452
Total	13,900	7,150	24,000	17,300	62,350

[1]Age distributions are estimated from a 1982 controlled sample of 170 local child welfare agencies (Maximus, 1983); populations are from Hill et al. (1987).

[2]Age distributions are estimated from a 1982 census study of 6,600 specialized foster care facilities (Hauber et al., 1984); populations are from Lakin, Hill, White, & Wright, (1988).

[3]Age distributions are estimated from a 1982 census study of 8,200 private and small public facilities (Lakin et al., 1985); populations are from Lakin et al. (1988).

[4]Age distributions are estimated from a 1985 census study of 270 state institutions (Scheerenberger, 1986); populations are from White, Lakin, Hill, Wright, & Bruininks (1987).

Footnotes

1. The development of this manuscript and the collection of information included in it was supported by the National Institute of Disability and Rehabilitation Research, U.S. Department of Education through its funding of the Research and Training Center on Community Integration at Syracuse University (Cooperative Agreement G0085C03503); and by the Administration on Developmental Disabilities, U.S. Department of Health and Human Services, through its funding of the Recurring Data Set Project (Grant 07DD0282/05) of the Minnesota University Affiliated Program. The opinions expressed are solely those of the authors and do not reflect endorsement of either government agency.

The authors would like to thank the staff of the Center on Human Policy, Ben Censoni and Sheri Falvay of the Michigan Department of Mental Health, Nancy Rosenau of the Macomb Oakland Regional Center, and Brad Hill for their assistance in identifying and understanding the issues discussed in this paper.

2. It now seems apparent that the county sampling strategy employed in estimating 500,000 children and youth in substitute care in 1977 was one that yielded a substantial overestimation. Fortunately, this "error" helped stimulate good public policy. More realistically about 260,000-270,000 children and youth were in substitute care in 1977 (see Hill, Lakin, Novak, & White, 1987).